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## **Perceived Barriers to Self-Management for People with Dementia in the Early Stages**

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## **Abstract**

People with dementia in the early stages currently experience a care-gap, which self-management may address. We explore perceived barriers to self-management. Using a systematic approach (logic mapping), 19 participants (people with dementia, carers, health-care professionals and charity representatives) described self-management barriers facing people living with dementia. Thematic content analysis revealed six main themes: the lived experience of dementia, diagnosis, role of carer/ family, impact of health-care professionals, organisation of health services and societal views. People with dementia were seen as passive recipients of care, unable to self-manage owing to impact of dementia on cognitive abilities. The need for interventions which are largely emotion focussed, encourage activity maintenance and improve quality of life were described. Barriers to self-management exist at multiple levels, suggesting a whole-systems approach is required.

## Introduction

Dementia is a chronic illness (National Audit Office, 2007) and is increasing in prevalence (Luengo-Fernandez, Leal, & Gray, 2010). Dementia has extensive cost and service implications and consequences for people living with dementia and family owing to losses in independence, decreased social activities and ability to initiate activities (Graff et al., 2006). Interventions to support people affected by dementia are required. Dementia is recognised internationally as a major health priority (Knapp, Comas-Herrera, Somani, & Banerjee, 2007). The first National Dementia Strategy for England (Department of Health, 2009) states the needs to improve good quality early diagnosis and intervention for all, development of structured peer support networks and improved community personal support services, issues which are mirrored in international policies (Rosow et al., 2011). However, there is currently a “care gap” as there are insufficient support services for people with dementia with less severe needs (National Audit Office, 2007). Self-management interventions are a possible solution to providing peer and community support in the early stages of the disease, as briefly acknowledged in the Scotland’s National Dementia Strategy (The Scottish Government, 2010), and may address the gap in care.

The goal of self-management is to live well with chronic illness, managing one’s condition and its emotional impact, in addition to maintaining as active a life as possible (J. Barlow, 2001). “Self-management support” is what health and social care services and professionals provide to facilitate patient’s to self-manage (Bodenheimer, MacGregor, & Shafiri, 2005). Self management behaviours include self-monitoring, seeking assistance and maintaining a positive outlook (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Self-management interventions can be group-based, and / or individualised and may include computer-assisted, mail-delivered, telephone and face-to-face components (J. Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Group self-management interventions have been shown to benefit a wide-range of patient groups (Foster, Taylor, Eldridge, Ramsay, & Griffiths, 2007; Lorig et al., 2008) and are a core part of UK Health policy and provision for

chronic conditions, to enhance health-related quality of life (Department of Health, 2010a). For people experiencing cognitive impairments, e.g. multiple sclerosis and Parkinson's disease, group self-management can be feasible and beneficial, (Gruber, Elman, & Huijbregts, 2008; Montgomery, Liberman, Singh, & Fries, 1994; Shevil & Finlayson, 2009).

There is little published research on self-management interventions for people living with dementia. Support groups, with an emphasis on social activities, sharing experiences with peers (Mather, 2006) and reciprocal support (Clare, Rowlands, & Quin, 2008) have been shown to be valued and beneficial. These findings are commonly reported in the self-management literature (J. Barlow, et al., 2002) thus supporting the potential feasibility and usefulness of a group self-management intervention for dementia. Owing to this potential benefit, the need to fill the "care gap" for people in the earlier stages (Department of Health, 2009) and the lack of research in the area, we sought to explore barriers to self-management among people living with dementia.

## **Methods**

### Recruitment and participants

Purposive sampling was used to gain the views of a range of participants (Renger & Hurley, 2006). Seven people with dementia (one female), two family members (both female) and two charity representatives were recruited through the Alzheimer's Society. Eight health care professionals working in dementia were interviewed: two Clinical Psychologists, two Community Psychiatric Nurses, two GPs and two Psychiatrists working in Older Adults services. Nineteen participants were interviewed individually or in small groups.

### Procedure

A logic modelling method "Antecedent Target Measurement" (ATM) (Renger & Hurley, 2006) was chosen to uncover barriers to self-management for dementia. This allows specification

of factors perceived as causing an issue (Cooksy, Gill, & Kelly, 2001). The first step of ATM was selected as a rapid and visual method of eliciting reasons for the lack of self-management for people with dementia. Interviews elicit “Antecedents” causing a problem (Renger & Hurley, 2006).

The “problem statement” (derived through consultation with Dr Bradbury, Consultant Clinical Psychologist, and representatives from Alzheimer’s Society) “People living with dementia are not generally encouraged to take an active role in managing their care” was used as an interview prompt. Having checked it was understood, participants were asked to give reasons why they felt the problem exists. Each reason or “antecedent” given was noted down and the participant was asked “why does this problem occur”, until they could add nothing further. Simple probes such as “who does this” were used to gain detail. Participants were also given the opportunity to disagree with the problem statement.

### Data Analysis

All antecedents generated were collated for analysis anonymously. Qualitative or thematic content analysis was chosen to explore and describe these short comments (Green & Thorogood, 2005) to classify the text into themes of similar meaning. Each antecedent was taken as a unit of analysis (Graneheim & Lundman, 2004). We applied an inductive approach to data coding. Codes were exhaustive and exclusive (Hsieh & Shannon, 2005). Two researchers (FM and KC) independently examined data to derive initial themes, which were then compared and disagreements in coding were discussed until consensus was reached.

### **Results**

Six themes were found, representing different levels from the individual with dementia to the service level and finally the societal level. Results are summarised in Table 1.

### Lived experience of dementia

Anxieties about losing memories, losing control and autonomy and deteriorating further were frequently mentioned. Memory loss was mentioned by many participants, including health care professionals, as a reason why self-management was not suitable for dementia because “people with dementia forget information given to them”. The very nature of dementia rendered self-management unhelpful. This forgetfulness meant that it is “not always feasible for people with dementia to play [an] active role”. Loss of abilities led to frustration and decreased “confidence”, “insecurity” and “low self-esteem”. Decreased awareness of one’s loss of capabilities was also mentioned, e.g. “Lack of insight, people with dementia generally feel well”, rendering self-management difficult owing to impaired self-monitoring.

### Impact of Diagnosis

Dementia is often diagnosed at a later stage, often after misdiagnosis as depression or normal ageing, with greater impairment meaning that “Diagnosis can be late – so unable to self-manage”. The impact of receiving a diagnosis was described as significant. Participants talked about “acceptance” as a challenge or simply avoided via denial – e.g. “No support for person with dementia to accept their condition” and “People with dementia and carers might be in denial”. Giving up was seen as a potential response to diagnosis, suggesting feelings of hopelessness.

### Role of carer, family and friends

Role change in relationships was mentioned, e.g. services “automatically label family / friend as carer”. Support required by family, friends and carers was discussed, including education and social support. Participants talked about “carer” inadvertently taking control away from the person with dementia, through trying to support them: “Carer might just do things for the person with dementia – the person gets no chance to self-manage”, which was connected to

the perceptions that without the “carer”, a task simply would not get done. Scepticism about the effectiveness of self-management was evident among carers and health care professionals, but not among people with dementia, owing to a lack of evidence to support self-management interventions.

### Impact of Health Care Professionals

Participants perceived health care professionals as finding it difficult to manage dementia: “Role of professional is assessment, diagnosis and referral, not therapy” and “Anxiety, health professionals need to do things for people, need to treat to be helpful”. Health care professionals talked about their professional desire to make people better and how this is simply not possible with dementia, leading to unwillingness to get involved and provide self-management support. Professionals’ unmet training needs were mentioned by the majority of participants. For example, “GPs feel they do not have sufficient training”. Health care professionals were seen as “unsure how to support people with dementia”, owing to the specialist nature of this area of care.

### Organisation of services

Health service related comments are in three sub-themes. First, infrequently mentioned but significant theme of “things that can work” does not represent barriers but is included to reflect the breadth of the data. This was exclusively mentioned by people living with dementia and covered positive impact of medication and clinicians who are there when required and “break down problems”. Availability of peer support was also seen as helpful. As a note of caution, some participants spoke of how support services can “...foster dependency” and thereby fail to support appropriate self-management.

Second, gaps in service provision were discussed, including a lack of services with a positive, enabling focus, e.g. “People with dementia are not enabled to use leisure outlets and services”. This deficit focus was specifically named: “Problem focussed, not strength



focussed, services". People with dementia were seen as passive recipients of care, who are disempowered by this deficit focus. One participant stated that services and society "assume that a person with dementia does not have abilities". These perceptions seem to underlie the lack of self-management support for dementia, as people who are seen as passive recipients of care cannot be also seen as able to actively self-manage. Providing self-management support was also considered to be a resource intensive intervention.

Third, health service infrastructure and policies related to a lack of national prioritisation, policy making and resource provision for people with dementia, thus limiting opportunities to self-manage. "Funding for care and activities for people with dementia is lacking". One participant specifically stated "Interventions are currently focussed on the carer, not the person with dementia". An overall lack of services was also perceived, e.g. "Memory clinics are not everywhere" and "No services available in appropriate language".

### Societal views

Public impressions of dementia was another barrier to self-management. Participants clearly and frequently mentioned "stigma". The public was described as fearful of dementia and seen as "using stigmatising language", which created anxiety about dementia, making people reluctant to seek support, thus affecting self-management. Several participants talked about a lack of information for all, describing society as "poorly informed about dementia, insufficient knowledge".

TABLE 1 about here

### **Discussion**

The study aimed to explore reasons why people with dementia were not encouraged to take an active role in managing their care, to explore barriers to self-management. Barriers were discussed by a range of participants, including people with dementia and their families, and

were found across multiple levels from the experience of living with dementia through roles of family and friends, to health services and public views.

The nature of dementia was a barrier to self-management. Specifically, dementia means that people “forget the information given to them”. Mountain’s (2006) review of self-management in dementia highlights similar issues, particularly the view that people with dementia will just forget any intervention. However, research has shown that in earlier stages of dementia, people can learn new information (Davis, 2005). Furthermore, self-management is not based solely on acquisition of new information and skills. Although skill acquisition can be important (C. Barlow, Cooke, Mulligan, Beck, & Newman, 2010), other self-management work emphasises enjoyment and engaging in pleasurable activities (Moniz Cook & Manthorpe, 2009a). Recent research has shown that people with moderate dementia may forget the details of an experience, but retain a positive feeling which impacts positively on quality of life (Trigg, Skevington, & Jones, 2007). This suggests that self-management interventions should focus more on promoting meaningful, positive experiences and outlook, with an emotion focus rather than a problem focus (Davies & Batehup, 2010).

Living with dementia included experiencing insecurities, low self-esteem and low confidence. Furthermore, participants spoke of hopelessness feelings sometimes surrounding diagnosis. Hope is important to quality of life, particularly so according to Kitwood’s conceptualisation of wellbeing with dementia (Kitwood, 1997). Self-management plays an important role in overcoming these barriers and improving quality of life (Barlow, Ellard, Hainsworth, Jones, & Fisher, 2005).

Participants reported late diagnosis as a barrier to self-management, stating that with more advanced dementia, self-management is no longer possible. The issue of late diagnosis is reflected in international dementia policies, reflected for example in the ongoing development of strategies for Ireland (Cahill, 2010), Australia (Travers, Martin-Khan, & Lie,

2009) and Canada (Knapp, et al., 2007). With England's National Dementia Strategy's (Department of Health, 2009) aim to improve early diagnosis, the potential usefulness of self-management interventions for people with dementia will increase as more people are diagnosed earlier, before major cognitive deficits develop. Diagnosis was described as a shock, with little support available, suggesting that self-management interventions may usefully be applied at the post-diagnosis point of need (Moniz Cook & Manthorpe, 2009b).

Labelling of a spouse as a "carer" creates a dramatic shift in personal relationships, which may prematurely disempower the person with dementia leading to low confidence and a withdrawal from pleasurable activities. This is supported by previous research (Cheston, Bender, & Byatt, 2000). However, in some cases family support can facilitate self-management. It has been remarked that the success of efforts of people with dementia to manage their identity will depend on support from others (MacRae, 2010, p. 301). Further research is required to understand the helpful and less helpful features of personal relationships which can then be the focus of skills training in self-management interventions.

Health care professionals and systems were barriers to self-management. Participants identified that interventions were available only for the "carer", further highlighting the need for interventions for the person living with dementia. Professionals were seen as uncertain how to support people with dementia. The need for education for health care professionals, specifically to support maintenance of independence and self-management is necessary, in addition to the more general training needs identified in England's National Dementia Strategy. These issues are also seen in other policies, including France and Korea (Rosow, et al., 2011) and is one of the minimum recommendations made in the internationally supported Kyoto Declaration (Prince et al., 2008).

Health care services were seen as sometimes fostering dependence through a deficit focus. Self-management, which focuses on retaining independence where possible, may prove a

powerful antidote to current service ethos. Further, participants detailed the lack of leisure and other services designed to promote wellbeing. Participation in leisure activities has been shown to improve wellbeing for people with dementia (Chung, 2004). Self-management includes such scheduling of pleasurable activities (Steverink, Lindenberg, & Slaets, 2008). Two issues are seen here: the need for training and systems to improve what professionals and services do to support self-management; and the need for provision of intervention to people with dementia to increase their own self-management.

Discussed in England's National Dementia Strategy and also acknowledged as a key issue in the Kyoto Declaration (Prince, et al., 2008), other national policies under development (Knapp, et al., 2007) and Scottish strategy (The Scottish Government, 2010), stigma was frequently mentioned, representing a challenge to and object of self-management. Stigmatised attitudes by health care professionals and service providers lead to a lack of support for self-management. Education is needed for public and professionals as to what living with dementia is like (Koch, Iliffe, & EVIDEM-ED Project, 2010). Stigma may drive late diagnosis, underpin beliefs that self-management is impossible for dementia and also provide a challenge to live with, causing a vicious circle of exclusion. Facing stigma everyday can reduce self-efficacy (Dilorio et al., 2003), damage one's sense of self (Jacoby, Snape, & Baker, 2005) and potentially lead to isolation and poor adjustment to illness (Bury, Newbould, & Taylor, 2005). Dealing with stigma then may form part of the task of self-management for people with dementia (Moniz Cook & Manthorpe, 2009b) as it does with other conditions such as epilepsy (Dilorio et al., 2004). Self-management interventions may be able to address the experience of stigma and how one can cope with this (Miles et al., 2003).

Of particular interest were barriers that people with dementia are seen as "passive recipients" of care and ideas that self-management is inappropriate. Disempowerment has been widely documented in dementia and acknowledged to potentially lead to further

disablement (Kitwood, 1990). In contrast, working with strengths and abilities of the person with dementia has been significantly improved relationships between the person and their family member/ carer (Peacock et al., 2009). Other interventions and services are beginning to use a strengths focus in the care of people living with dementia (e.g. Cotrell, 2007) to provide self-management support and to teach self-management skills to people with dementia.

The study has several limitations. The problem statement “People with dementia are not generally encouraged to take an active role in managing their care” did not specify a type of dementia, age of onset or stage of dementia. As participants stated, a later stage dementia may preclude self-management because of the nature of the illness. However there may be different barriers to self-management for different types of dementia, which manifest themselves through different signs and symptoms. Further work could elucidate these differences. Although the sample size (N=19) for this research was small, this is above recommendations of 12 interviews for data saturation (Renger & Hurley, 2006) and a range of people involved in dementia care was represented. The comments are inherently subjective, however we sought to explore perceived barriers using ATM provide root cause analysis of barriers. Data gained are short statements, which do not provide the “thick” descriptions in other qualitative work. However explorations of experiences of living with dementia have already been undertaken. For example, in-depth focus groups and interviews conducted highlighted difficulties of gaining a diagnosis, lack of support and information, and lack of understanding of dementia by GPs and general public (Alzheimer's Society & Mental Health Foundation, 2008), which reflects our results. The current study explores these issues specifically in relation to self-management.

A therapeutic nihilism still exists. Participants reported perceptions that nothing can be done and self-management is pointless because people with dementia would forget the intervention. These evidence not only a misconception of what living with dementia in the

earlier stages is like and what can be done to improve quality of life but also a limited and narrow view of what self-management interventions entail. The features of dementia undoubtedly present a challenge to self-management, both interventions for people with dementia and training and systems to improve self-management support given by health and social professionals and family members. Interventions for people with dementia may require adaptations to reduce cognitive load, to be tailored to individual's strengths and emphasise meaningful and pleasurable activity. Perceptions that self-management is not well evidenced, in general and specifically for dementia, can only be addressed through systematic research in this area to explore the feasibility and effectiveness of self-management interventions for people with dementia. The current barriers render such research challenging. The data presented here will inform development of evidence-based, self-management interventions, which will be useful for the many people to be diagnosed with early stage dementia in coming years. England's National Dementia Strategy's quality outcomes framework includes people with dementia knowing what they can do to help themselves and being able to enjoy life (Department of Health, 2010b). Addressing the barriers we have identified and supporting self-management may help achieve these important outcomes.

**Table 1 Themes and subthemes with illustrative quotes**

Themes and subthemes	Illustrative quotes
<p>Lived Experience of dementia</p> <p>Worries and fears</p> <p>Aspects of illness that may affect treatment and ability to self-manage</p>	<p>“Shame, anger, frustration, afraid of losing identity”</p> <p>“Afraid of deterioration and failure”</p> <p>“Concerned about becoming a burden for their family”</p> <p>“Fear of losing memory”</p> <p>“A person with dementia is forgetful”</p> <p>“Lack of insight: people with dementia do not generally feel ill”</p> <p>“Not always feasible for people with dementia to play an active role [owing to their condition]”</p> <p>“Planning is hard for people with dementia”</p> <p>“People with dementia forget information given to them”</p> <p>“Not aware of what people can still do”</p> <p>“Focus on disabilities rather than abilities”</p>
<p>Diagnosis</p> <p>Getting a diagnosis</p>	<p>“People with dementia do not come forward”</p> <p>“Late diagnosis is common”</p> <p>“Misdiagnosed as depression or anxiety”</p> <p>“Misattribute to normal ageing”</p> <p>“Nothing can be done – why give the diagnosis”</p>

Coping with diagnosis	<p>“Diagnosis is a big shock”</p> <p>“Not every person with dementia accepts their condition”</p> <p>“Person with dementia and carers might be in denial and not accepted diagnosis”</p>
Carer, family and friends	<p>“Carer might just do things for the person with dementia – the person with dementia gets no chance to self-manage”</p> <p>“Labelling (i.e. “patient”, “carer”) changes relationships with family and friends”</p> <p>“Social circle might be lost”</p> <p>“Family support the person with dementia”</p> <p>“Friends and social circle need to be educated”</p>
<p>Health Care Professionals</p> <p>Features of health care professionals</p> <p>Professional’s training needs</p>	<p>“Health care professionals are anxious / reluctant to get too close to people with dementia”</p> <p>“Role of the professional is assessment, diagnosis, referral – not therapy”</p> <p>“Some clinicians are understanding”</p> <p>“Doctors just do tests, they’re not very interested in helping”</p> <p>“GPs lack knowledge and understanding of dementia”</p> <p>“GPs feel they do not have the specialist training”</p> <p>“Elderly care / dementia care is a specialist area”</p>



	<p>“Health care professionals do not have the information”</p> <p>“Little knowledge/ acceptance of what people with dementia can do to self-manage”</p>
Health Services	
Aspects that can work	<p>“Clinicians break down problems”</p> <p>“Medication has a positive impact”</p> <p>“Peer support can develop to friendship”</p> <p>“Some clinicians (mental health nurses) are there when needed”</p>
Gaps in service provision	<p>“No social support or social activities for people with dementia”</p> <p>“People with dementia are not enabled to use leisure outlets and services”</p> <p>“Not enough Admiral nurses”</p> <p>“Memory clinics are not everywhere”</p> <p>“Problem focused not strength focused services”</p> <p>“[Currently] focus on improving condition, not quality of life”</p> <p>“Time of [GP] appointment is limited to 10 mins”</p> <p>“People with dementia are not receiving adequate treatment to be able to self-manage”</p>
Infrastructure and policies	<p>“Not enough funding to support self-care initiatives”</p>

	<p>“Primary care is crisis driven and reactionary”</p> <p>“Interventions currently focus on carer, not person with dementia”</p> <p>“Have to deal with large case loads”</p> <p>“Traditional solutions are problem- and not emotion-focussed”</p> <p>“People with dementia are seen as passive recipients of care”</p>
Societal views	
Public impression of dementia	<p>“Low awareness and high fear of dementia”</p> <p>“Stigma”</p> <p>“Dementia is not acceptable to talk about”</p> <p>“We keep people with dementia hidden”</p> <p>“Nothing can be done attitude”</p>
Lack of information (for all)	<p>“[Public and professionals] Poorly informed about dementia”</p> <p>“Not enough information in the public arena – until recently dementia was not in the media”</p> <p>“Health care professionals don’t give out information”</p>

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